Multidimensional fatigue during rehabilitation in persons with recently acquired spinal cord injury

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ORIGINAL REPORT

MULTIDIMENSIONAL FATIGUE DURING REHABILITATION IN PERSONS WITH RECENTLY ACQUIRED SPINAL CORD INJURY

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Objectives: **To examine the change in multidimensional fatigue in people with spinal cord injury during post-acute rehabilitation, and to compare these scores with those of healthy adults. Furthermore, to examine correlations between different dimensions of fatigue at discharge and demographics, injury-related variables and indices of psychological adjustment.**

Design: **Longitudinal cohort study.**

Subjects: **From 86 patients admitted for spinal cord injury rehabilitation, between June 2011 and January 2013, 78 met the inclusion criteria, and 70 (90%) agreed to participate.**

Methods: **Self-reported questionnaires were completed at admission and in the week before discharge. Questionnaires used assessed demographics, injury-related variables, multidimensional fatigue, and psychological adjustment.**

Results: **At admission, fatigue scores were very high and decreased significantly during rehabilitation. At discharge, fatigue scores were still significantly higher than those of healthy adults. The fatigue total score at discharge was weakly associated with demographic variables and injury-related variables. Psychological adjustment variables explained the largest proportion of variance of the fatigue total score and each of the subscales.**

Conclusion: **Fatigue is an important consequence in people with recently acquired spinal cord injury. Associations between fatigue and psychological adjustment suggest that psychological interventions might be useful to diminish fatigue.**

Key words: spinal cord injuries; fatigue; psychological functioning; rehabilitation.

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INTRODUCTION

Fatigue can be defined as a state of excessive chronic tiredness and a pervasive feeling of exhaustion (1–3). In the last decade, a growing number of qualitative and quantitative studies have underlined the importance of fatigue in persons with spinal cord injury (SCI). Jensen et al. (4) found that 67% of people with chronic SCI reported fatigue, of whom 18% reported severe fatigue. Saunders & Krause (5) reported considerably lower percentages, of 46.4% and 8.3%, respectively. In other studies, over 50% of people with SCI reported fatigue severe enough to interfere with functioning (1, 6–8).

Qualitative studies have shown that fatigue is very commonly experienced by people with SCI (9), and is perceived as having a negative effect on a patient's life (10). This is corroborated in quantitative cross-sectional studies, which report negative associations of fatigue with quality of life (1, 11), social and psychological functioning (4), and rehabilitation outcomes (12). In addition, fatigue has been reported to be associated with pain (1, 3, 6), depression (2–3, 7, 13–15), anxiety (2), injury severity (5–6), age (5, 11, 16), and medication (5, 8, 14).

Some issues related to fatigue in people with SCI have, however, not been addressed in the literature to date. First, the prevalence of fatigue in people with SCI in post-acute rehabilitation is unclear. Most previously published studies into fatigue have been about the chronic situation. Studies into the post-acute phase call for more research into the nature and impact of fatigue and other factors that complicate treatment sessions (12). Secondly, little is known about the course of fatigue in people with SCI. Some cross-sectional correlation studies have reported higher levels of fatigue in patients with shorter duration of SCI (1, 3, 11), while other studies failed to support these finding (4, 15, 17). Longitudinal studies are therefore needed to draw conclusions about the course of fatigue over time. Thirdly, fatigue in SCI is commonly assessed with single-item measures of the subjective level of fatigue (6–7, 15, 18) or with unidimensional questionnaires, such as the Fatigue Severity Scale (FSS) (6–8, 10, 13, 19), that measure the impact of fatigue on functioning. Lidal et al. (14) and Craig et al. (3) have used a multidimensional questionnaire that included both physical and mental fatigue subscales. Hammell et al. (10) showed that fatigue also has cognitive and emotional dimensions. Fourthly, it is unknown whether and how these various dimensions of fatigue are associated with psychological functioning in people with SCI.

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The first aim was to examine the change in fatigue between admission and discharge from the first inpatient rehabilitation phase, and to compare fatigue scores at discharge with reference scores of healthy adults. It is hypothesized that levels of fatigue will be high at the start of the rehabilitation and will decrease over time, but will still be higher at discharge compared with fatigue in healthy adults (1–2, 4–8, 10, 16–18). The second aim was to examine correlations of different dimensions of fatigue at discharge with demographic variables, SCI-related variables and several psychological adjustment indices, and to assess the amount of explained variance of these determinants. It is hypothesized that fatigue is not related to demographic variables (1–2, 5, 8, 14), only moderately related to SCI-related variables (1, 3, 5–6, 10), and strongly related to psychological adjustment variables (2–3, 7, 10, 13–15).

METHODS

Participants

All patients with a recently acquired SCI who were admitted for inpatient rehabilitation to the Sint Maartenskliniek in Nijmegen, the Netherlands, between June 2011 and January 2013 were considered for inclusion in the present study, with the exception of patients with cancer-related SCI who had a short life expectancy. This clinic is one of 8 sites in the Netherlands that specialize in SCI rehabilitation. In this period, a total of 86 people with a recently acquired SCI were admitted to the rehabilitation centre. Patients were excluded from this study if they were delirious during the first weeks of admission, had severe psychiatric, cognitive or intellectual problems, or if they were not able to read Dutch according to the rehabilitation physician and the ward psychologist. For the present study, only cases with complete data on admission and discharge were analysed.

Procedure

The ward psychologist contacted the patients in the first week of their admission in the Sint Maartenskliniek, and patients were asked to complete a set of psychological questionnaires for diagnostic purposes as part of routine care. At the same time, patients were informed about the purpose and contents of this study. It was explained to them that enrolment in the study would mean that their responses would be used for research purposes, and that they would be asked to complete the same set of questionnaires in the week before discharge. A patient who was not able to write because of hand function problems was asked to complete the questionnaires with the help of a partner or other trusted person. If no such person was available, a clinical psychologist's assistant supported them.

All participants gave written informed consent. The local medical ethics committee approved the research protocol.

Measures

Demographic variables. Age, sex, living with a partner, educational level and work were assessed.

SCI characteristics. Time since injury; cause of the lesion: divided into traumatic (traffic accident, industrial accident, sports accident, fall from height, gunshot – or stab wound) and non-traumatic (disease-related or resulting from medical procedure); level and type of injury according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A, B, C or D of the SCI were determined by a trained rehabilitation physician at admission.

Pain. Pain was measured with a visual analogue scale (VAS 100 mm).

Multidimensional fatigue. The Checklist Individual Strength (CIS) was used to measure fatigue. This 20-item questionnaire consists of 4 scales: Subjective experience of fatigue (8 items); Reduced concentration, referring to the cognitive aspects of fatigue (5 items); Motivation, referring to the emotional aspects of fatigue (4 items); and Physical activity level (3 items). Each item is scored on a 7-point Likert scale ranging from "Yes, that is true" to "No that is not true". In addition to the 4 scale scores, a total score of all the 20 items can be calculated. Higher scores on a (sub)scale reflect a higher degree of fatigue. The psychometric properties in various patient groups (including neurological disorders, other than SCI) and healthy adults are excellent (20–22).

Psychological adjustment. This was operationalized as distress and illness cognitions.

Distress was assessed using the Hospital Anxiety and Depression Scale (HADS). The HADS is a commonly used measure of distress and contains 14 statements with 7 items each measuring depressive mood or anxiety. Participants were asked to what degree they agreed with each statement on a 4-point scale (23–24). Higher scores on a scale reflect more symptoms of anxiety and depression, respectively. The HADS has been shown to be a reliable and valid instrument in SCI research (25–26).

Illness cognitions were assessed using an adapted version of the Illness Cognitions Questionnaire (ICQ) (27–29). This instrument contains 18 statements divided into 3 scales: Helplessness, which measures the aversive cognitive attributions attached to the SCI; Acceptance, which measures neutralizing connotations of the condition; and Disease benefits, which measures the positive meaning given to the SCI. Participants were asked to what degree they agreed with each statement, ranging from 1 (not at all) to 4 (completely). A higher score on the Helplessness scale reflects more negative cognition, while on the other 2 scales a higher score reflects more positive illness cognition. With the adapted version of the ICQ used here, Wollaars et al. (29) found good internal consistency of the different scales in persons with SCI.

Statistical analyses

The sample is described by numbers and percentages for categorical variables, and median, and quartiles for continuous variables. Because this is the first time that the CIS has been used to assess fatigue in SCI, internal consistency of the CIS scales was assessed using Cronbach's alpha. All the assessment scales used in this study have ordinal scores; therefore we used only non-parametric statistics.

To analyse changes in scores between admission and discharge, Wilcoxon signed-ranks tests were used. Wilcoxon signed-ranks tests were used also to compare the scores on the CIS with healthy adults (described by Vercoulen et al. (22)).

Secondly, we used the discharge data to analyse the relationships between the CIS scores and demographic, SCI-related, and psychological adjustment variables. Associations were expressed in Spearman correlations; correlations up to 0.3 are considered as weak, between 0.3 and 0.5 as moderate, and above 0.5 as strong (30). To determine which independent variable should be used in a multivariate regression analyses, univariate regression analyses were performed with all potential independent variables. The variables with a p-value below 0.25 were used in a multivariate regression analyses and entered block-wise. First, all the relevant demographic variables were entered simultaneously. In the second block all relevant SCI-related variables were entered simultaneously and, finally, all relevant psychological variables. Associations between the 3 blocks of variables and fatigue scores were expressed as the percentage of variance (R^2) explained by all variables in that block corrected for the variables in the previous block(s). R^2 up to 0.25 are considered as small associations, from 0.25 to 0.40 as moderate, and above 0.40 as large (30).

p-values less than 0.05 were considered statistically significant in the analyses. All analyses were conducted using SPSS statistical program for Windows (version 16.0) (SPSS Inc, Chicago IL, USA).

Table I. *Characteristics of the patients in the study (*n = *64)*

Characteristics	
Age, years, mean (SD) [range]	55.2 (14.7) [22–80]
Duration of injury at admission, days, mean (SD) [range]	43.8 (34.6) [11–153]
Duration of stay, days, mean (SD) [range]	75.0 (52.6) [12–289]
Sex, male, *n* (%)	33 (51.6)
Injury level, *n* (%)	
Cervical	26 (40.6)
Thoracic	24 (37.5)
Lumbo-sacral	14 (21.9)
Completeness, *n* (%)	
AIS A	19 (29.7)
AIS B	4 (6.2)
AIS C	10 (15.6)
AIS D	31 (48.4)
Cause of injury (traumatic), *n* (%)	24 (37.5)
Living with a partner, *n* (%)	47 (73.4)
Education level, *n* (%)	
Higher education	15 (23.4)
Medium education	29 (45.3)
Lower education	20 (31.3)
In paid employment before SCI, *n* (%)	22 (34.4)

AIS: ASIA Impairment Scale; SCI: spinal cord injury; SD: standard deviation.

RESULTS

Of the 86 eligible patients, 8 were excluded from the study: 2 were delirious, 2 could not read Dutch, 3 had cognitive or intellectual problems, and 1 was transferred because of serious medical complications soon after admission. The remaining 78 patients were invited to participate, 70 (90%) agreed to do so and 67 completed the questionnaires for the second time in the week before discharge (2 patients did not return the questionnaire, and 1 was admitted for only a short period of time). Table I gives the characteristics of the patients with complete data on both measurements ($n = 64$).

Table I shows that the mean age in this sample was relatively high, and few people had a paid job at the time of the SCI, in part because many were already in (early) retirement. Differently from most other SCI studies, sex was almost equally divided in this sample. The education level was as expected in the Netherlands.

The internal consistency of the CIS scales was satisfactory to excellent, with Cronbach's alpha at admission of 0.93 for subjective experience of fatigue; 0.91 for reduced concentration; 0.83 for motivation; 0.69 for physical activity level; and 0.93 for the total CIS score.

Table II shows the median and interquartile range at admission and discharge for the CIS and for the psychological adjustment variables.

Between admission and discharge, all scores on the CIS decreased significantly, with the largest decrease reported in subjective experience of fatigue and the smallest for reduced concentration. Significant differences between assessment at admission and discharge were also observed in the pain score (VAS) and all the adjustment variables.

Compared with healthy adults (22), the scores on all the fatigue scales were significantly higher both at admission and at discharge (at discharge: total $Z = 5.2$, $p < 0.001$; subjective $Z = 5.0$, $p = 0.001$; concentration $Z = 3.4$, $p = 0.001$; motivation $Z = 4.4$, $p < 0.001$; activity $Z = 5.1$, $p < 0.001$).

Also, reported levels of distress in the sample were high. Using cut-off scores of 8 points on both HADS subscales (31), 31% of the people in this sample showed probable depression and 34% showed probable anxiety disorder at admission. At discharge these percentages were 16% and 20%, respectively.

In Table III the Spearman correlation coefficients are depicted between the potential independent variables and the fatigue scales.

Most demographic variables showed weak associations with the fatigue variables, except for "having a partner at discharge", which showed moderate associations. From the SCI-related variables only pain was moderately associated with the total fatigue scale and with the subjective experience of fatigue. Depression and anxiety had the strongest and almost equal associations with CIS scores, reflected in moderate to strong

Table II. *Median and interquartile range (IQR) at admission and discharge for the fatigue scales, pain and the psychological adjustment scales, the Z-value according to the Wilcoxon signed-ranks test (*n = *64). For the Checklist Individual Strength (CIS) the reference scores are also displayed*

	Admission		Discharge		Wilcoxon		Reference
	Median	IQR	Median	IQR	Z-value	*p*	Mean (SD)
Fatigue (CIS)							
Total fatigue score	83.5	65.0–102.25	62.0	44.5–83.75	–4.60	0.000**	41.5 (19.8)
Subjective experience	38.0	28.0–48.75	26.0	16.0–37.5	–5.29	0.000**	17.3 (10.1)
Concentration	16.0	7.25–24.0	12.5	6.0–21.0	–2.11	0.035*	9.5 (5.0)
Motivation	13.0	9.25–17.75	10.0	7.25–17.0	–3.09	0.002**	7.9 (4.1)
Physical activity level	15.0	11.0–18.0	10.0	7.0–15.0	–4.09	0.000**	6.6 (4.5)
Pain (VAS)	21.0	7.0–45.0	12.0	3.0–23.0	–3.55	0.000**	
Psychological adjustment							
Depression	6.0	4.0–10.0	5.0	2.0–7.75	–3.05	0.002**	
Anxiety	6.0	3.0–10.0	4.0	2.0–8.0	–3.08	0.002**	
Acceptance	12.0	10.0–15.0	15.0	13.0–18.0	–4.79	0.000**	
Helplessness	15.5	12.0–19.0	13.0	10.0–17.0	–4.40	0.000**	
Disease benefits	13.0	10.0–17.0	15.0	13.0–18.0	–3.55	0.000**	

*$p < 0.05$, **$p < 0.01$ according to Wilcoxon signed-ranks test.
VAS: visual analogue scale; SD: standard deviation.

Table III. *Spearman correlation coefficients between the potential independent variables and the fatigue scales (*n = *64)*

	CIS Total	CIS Subjective	CIS Concentration	CIS Motivation	CIS Physical activity
Age	0.13	0.09	0.12	0.09	0.07
Sex	0.25*	0.24	0.23	0.21	0.14
Partner at discharge	0.21	0.10	0.19	0.32**	0.21
Education	–0.21	–0.18	–0.14	–0.23	–0.03
Paid job	0.13	0.06	0.09	0.14	0.14
Level of SCI	0.10	0.12	–0.05	0.17	0.15
Completeness of SCI	–0.03	–0.01	–0.03	0.04	–0.02
Traumatic SCI	0.08	–0.02	0.22	0.01	–0.04
Duration of stay	0.24	0.17	0.22	0.28*	0.19
Pain (VAS)	0.35**	0.43**	0.21	0.19	0.07
Depression	0.66**	0.57**	0.56**	0.56**	0.39**
Anxiety	0.66**	0.59**	0.55**	0.67**	0.36**
Acceptance	–0.45**	–0.40**	–0.37**	–0.44**	–0.36**
Helplessness	0.35**	0.28*	0.20	0.31*	0.40**
Disease benefits	–0.24	–0.10	–0.27*	–0.28*	–0.28*

*$p < 0.05$, **$p < 0.01$ according to Spearman correlation analysis.
CIS: Checklist Individual Strength; VAS: visual analogue scale; SCI: spinal cord injury.

correlations with all fatigue subscales. Higher levels of acceptance were associated with lower levels of fatigue. Acceptance was moderately associated with each of the fatigue subscales. Helplessness and Diseases benefits were moderate to weakly associated with CIS total score and the subscales.

Table IV shows the results of the multivariate regression analyses. The block of demographic variables explained a small proportion of the variation of fatigue at discharge (13% of the CIS total score). Females, on average, reported higher levels of fatigue on the CIS total score (median 79.0 vs 55.0, Mann-Whitney *U* test Z = –2.0, $p = 0.047$), subjective experience of fatigue (32.0 vs 23.0, Z = –1.9, $p = 0.063$), reduced concentration (16.0 vs 10.0, Z = –1.8, $p = 0.066$), and motivation (14.0 vs 9.0, Z = –1.7, $p = 0.092$). Patients with a partner reported lower levels of CIS total fatigue (54.5 vs 78.0, Z = –1.7, $p = 0.089$), concentration (11.5 vs 18.0, Z = –1.5, $p = 0.139$) and motivation (8.5 vs 16.0, Z = –2.6, $p = 0.011$).

The SCI-related variables together explained an additional 12% of the variance of the total CIS score corrected for the relevant demographic variables.

All psychological adjustment variables together explained an additional 31% of the variance of the total CIS score and 16–27% of the scores on the subscales.

The 25% of the participants ($n = 16$) who improved the most on the total fatigue scale from admission to discharge did not significantly differ in any of the demographic or SCI-related variables from the rest of the participants. Pain nearly reached significance, with less pain for the participants who improved the

Table IV. *Regression analyses with the fatigue scales as dependent variables, entering block wise the demographic, spinal cord injury (SCI)-related variables and the psychological adjustment variables. R2 depicted for each group of variables, corrected for the variables in the previous block(s) (*n = *64)*

CIS	Total	Subjective	Concentration	Motivation	Physical activity
Demographic variables					
				Sex	
				Partner at discharge	Sex
	Sex		Sex	Paid work	Partner at discharge
	Partner at discharge	Sex	Partner at discharge	Education	Education
R^2	0.13*	0.07*	0.10*	0.20**	0.06
SCI-related variables					
			Level of SCI		
			Traumatic SCI		Completeness of SCI
	Pain	Pain	Pain	Pain	Duration of stay
R^2	0.12**	0.15**	0.12*	0.04	0.10*
Psychological adjustment					
	Depression	Depression	Depression	Depression	
	Anxiety	Anxiety	Anxiety	Anxiety	Anxiety
	Acceptance	Acceptance	Acceptance	Acceptance	Acceptance
	Helplessness	Helplessness	Helplessness	Helplessness	Helplessness
	Disease benefits	Disease benefits	Disease benefits	Disease benefits	Disease benefits
R^2	0.31**	0.24**	0.27**	0.27**	0.16*

*$p < 0.05$, **$p < 0.01$.

most. From the psychological adjustment variables, only anxiety reached significance, and depression approached significance.

DISCUSSION

This is the first longitudinal cohort study into multidimensional fatigue in the sub-acute phase of people with SCI in relation to psychological adjustment.

The first aim was to examine the change in the different dimensions of fatigue during post-acute rehabilitation, and to compare these scores with scores of healthy adults. At the start of inpatient rehabilitation, people with a recently acquired SCI reported levels of fatigue almost twice as high as healthy adults on all CIS scales. During rehabilitation there was a significant decrease in all CIS scores. Despite this decrease, fatigue scores were still significantly higher than those of healthy adults at discharge. These findings corroborate earlier studies reporting high levels of unidimensional fatigue in people with SCI more than one year after the injury (1–2, 4–8, 10, 16–18). Our findings also indicate that fatigue at the start of the rehabilitation is higher than fatigue reported in the chronic phase of SCI, for all dimensions.

The second aim was to examine correlations of different dimensions of fatigue with demographics variables, SCI-related variables and the psychological adjustment indices at discharge, and to assess the amount of explained variance of fatigue. The psychological adjustment variables taken together explained the largest proportion of variation in fatigue (an additional 31% of the CIS total after correction for demographic and SCI-related variables). Depression and anxiety, in particular, had strong correlations with the fatigue total score, and moderate to strong associations with all the fatigue subscales. Low levels of anxiety seem to play an important role in improving from fatigue. The illness cognitions had a moderate to weak association with the CIS total score and the subscales. The blocks of demographic- and SCI-related variables explained small proportions of the variations in some of the CIS (sub)scales. It seems that psychological adjustment plays an important role in all the different dimensions of fatigue. The same was found in another study that used a multidimensional fatigue scale (14).

Of the SCI-related variables, pain was moderately correlated with 2 fatigue scales (total fatigue and subjective fatigue). The influence of pain on fatigue is corroborated in earlier studies (1, 3, 6). The strong relation between psychological adjustment and fatigue has been observed before in patients with SCI in the chronic phase (2–3, 13–15). Craig et al. (3) found that depressed mood contributed, independently from pain, to the experience of fatigue. Our data suggest that not only depression, but also anxiety and illness cognitions are related to fatigue in the rehabilitation phase.

The correlation of the total CIS score with the demographic variables was mostly due to reduced concentration and motivation. For the SCI-related variables, the correlation with the total CIS score was mostly due to subjective experience of fatigue and reduced concentration. For the correlation of the psychological adjustment indices with the total CIS score, all subscales contributed, although not all to the same extent. These results suggest that the different subscales measure different aspects of fatigue, and together provide more comprehensive information about fatigue than does a unidimensional measurement like the FSS (7, 10).

One of the limitations of the study is that the sample size of this study is small; only 64 people with a recently acquired SCI. To draw stronger conclusions about the course of fatigue over time, a larger sample is needed, also a longer follow-up period, for instance one year after discharge. The study sample is representative for people in inpatient rehabilitation in the Netherlands, but compared with the international literature (1–2, 4–11, 13–16, 18) this sample is relatively old, and contains a higher proportion of females. This difference can partly be explained by the high proportion of patients with non-traumatic SCI. However, patients with traumatic SCI in this study did not differ in fatigue from patients with non-traumatic SCI. Nonetheless, one should be careful about generalizing from these findings. Another limitation is that physical capacity was not measured in this study, nor did we have information about medication, sleep (quality), spasms or bladder and bowel function, or other secondary complications (except pain) that may influence the experience of fatigue. Furthermore, the influence of other psychological factors, such as coping with the SCI, has not been taken into account.

It would be desirable to make a distinction between fatigue that improves over time and more chronic fatigue. Further research with the CIS could focus on this subject.

Fatigue is an important variable in rehabilitation outcome (12), showing negative associations with quality of life (1, 11). Therefore, it is important to identify people with high levels of fatigue early in the rehabilitation. As yet, there are no specific interventions for the treatment of fatigue in SCI, besides reconditioning. Cognitive behavioural therapy (CBT) can be used to reduce negative feelings through cognitive restructuring. In the treatment of chronic fatigue syndrome, CBT has been shown to be effective (32). In SCI, the early treatment of fatigue is important for the rehabilitation process itself, and in order to reduce stay in the rehabilitation (12). In SCI, an early treatment of fatigue is especially of interest because persons with SCI who are fatigued in the chronic phase remain fatigued (4).

In conclusion, fatigue is an important consequence of SCI. Different aspects of fatigue can be distinguished. At discharge, psychological adjustment explains a large proportion of the variance in fatigue. This suggests that psychological interventions might help to diminish the experience of fatigue in this group. Further research is needed to investigate effective ways to treat fatigue for people with SCI. Although the different scales for psychological adjustment used in this study depict partially overlapping constructs, it is safe to conclude that there is an important role for psychological variables in SCI-related fatigue.

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